Why racial and ethnic data on COVID-19’s impact is badly needed

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Aletha Maybank, MD, MPH
Chief Health Equity Officer and Vice President

The COVID-19 global pandemic has taken tens of thousands of lives around the world. Here in the U.S., we at the AMA have repeatedly and consistently demanded urgent action to address the tragic shortages of essentials such as timely diagnostic testing, personal protective equipment and ventilators that are impeding our physicians’ efforts to save lives. There is another shortage that desperately requires our nation’s attention: a lack of public data on the racial and ethnic dimensions of this deadly respiratory illness.

So far, less than a dozen states have publicly shared information on the racial and ethnic patterns of COVID-19. Yet what has emerged so far paints an alarming portrait.

Michigan’s newly released data raises particular alarm with a disproportionate percentage, 35% and 40% respectively, of cases and deaths happening among blacks. In Wisconsin’s Milwaukee County, half of the cases and 81% of the deaths were amongst blacks, when blacks only make up only a quarter of the population. In Chicago, seven in 10 COVID-related deaths were among blacks while blacks constitute less than one-third of the city’s population.

The AMA is urgently calling upon the U.S. Department of Health and Human Services and its subagencies, state and local health departments, health care institutions, and laboratories to standardize, collect and immediately make publicly available existing race and ethnicity data so that we can begin to prioritize equity and effectively manage this pandemic.

Data drives optimal response

Having race and ethnicity data is at the heart of understanding injustice in health and health care and ensuring optimal health, and fairness, for all people in this country. But it is gravely missing in this public health crisis—missing from health department reports and websites, from daily updates by
political and health leaders, and, until recently, from news media summaries. Our fear is that COVID-19’s impact will widen existing health gaps while going unnoticed by us in healthcare and public health.

We need data disaggregated by race and ethnicity on who receives tests, who tests positive, who is hospitalized, who dies, and, once developed, who receives treatment and a vaccine, along with who participated in clinical trials which historically lack representation for black and brown people.

Without timely and accessible data on the race and ethnicity patterning of the pandemic, we limit our capability to:

- Understand this pandemic to its fullest extent.
- Focus efforts and messaging that are culturally responsive and appropriate that quell misinformation and fears.
- Ensure equitable access to testing and treatment.
- Ensure equitable distribution of resources in the present and for future emergency preparedness and response.

Let’s be clear. The initial slow response, current chaos, and mass confusion around testing—from inequitable access to kits, to unclear processing guidelines, to backlogs of performed tests, to name a few—are unwieldy and do not create an optimal data testing environment for us to fully understand coronavirus, SARS-CoV-2, and its corresponding disease, COVID-19—for anybody. Period.

**Improving testing access**

And while testing prioritization of those who are critically ill and hospitalized is the necessary and appropriate protocol, we are further missing the opportunity to test those who may be exposed to coronavirus. This only serves to more deeply challenge the accurate and consistent capture and public release of race and ethnicity data.

And this is further fueled by the concern that those minoritized and most marginalized, such as communities of color, may not have access to testing equal to others and may harbor distrust for the health care system, preventing them from seeking care. This is an absolute recipe for undercounting and misrepresentation, keeping invisible social and structural harms and actual disease burden.

**Addressing structural inequities**
Our call for the immediate reporting of racial and ethnic data is not based on a biological argument describing differential susceptibility to the coronavirus among racial lines. Our call, instead, is based on widely known history and evidence in medicine and public health that all too often institutions of health and health care in this country were designed to discriminate against the social condition of race whether poor or not.

Throughout our country’s history, communities of color have experienced the consequences of structural inequities in health care, wealth, housing and education, to name a few, caused by racism. It is our scientific data in health and public health, along with the experiences and stories from everyday people, that sheds light on these realities. These well-documented structural inequities have made communities of color vulnerable and susceptible to chronic heart disease, diabetes and obesity. All underlying conditions that make one more vulnerable to major complications with COVID-19.

The nature of infectious disease lays out the course for effective public health practice and policy. Any effective plan to contain the spread of COVID-19 must understand its spread and impact amongst communities of color and others marginalized in society. If we ignore these rifts of structured inequities, we will ultimately increase the burden of disease not only for minoritized and marginalized people, but for everyone.